

ANNUAL STATUS REPORT

Of The

**Commission on Services and Supports for
Individuals with Mental Retardation and Other
Developmental Disabilities**

Established By

**H.B. 144 of the 2000 General Assembly
(KRS 210.577)**

OCTOBER 1, 2002

The following report is in response to the mandates as stated in KRS 210.577 and provides updated information regarding the past year, October 1, 2001-September 30, 2002.

KRS 210.577: (1) The commission created in Section 2 of this Act shall meet at least quarterly during the 2000-2001 biennium, at least biennially thereafter, or upon the call of the chair, the request of four (4) or more members, or the request of the Governor.

- Since the last Annual Status Report, the Commission has held four meetings. These meetings were held on November 20, 2001, February 14, 2002, June 11, 2002, and August 20, 2002.

KRS 210.577: (2) The commission shall serve in an advisory capacity to accomplish the following:

(a) Advise the Governor and the General Assembly concerning the needs of persons with mental retardation and other developmental disabilities;

- The ten-year plan specifies the need for a system that will have the capacity to provide the needed components of a comprehensive package of services for between 8,000 and 10,000 Kentuckians with mental retardation and other developmental disabilities.¹ The capacity, at the end of the FY 01-02 biennium, for comprehensive services to this population was 2902, (1,932 in the Supports for Community Living program and 970 in facilities).

¹ Calculation based upon estimated need for comprehensive services for 200-250 people per 100,000 population. Published by the National Association of State Directors of Developmental Disabilities Services in *Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports*, Gary Smith, November 1, 1999.

- Particular supports/services needed by persons with mental retardation and other developmental disabilities and prioritized by the Commission are as follows: Day/Community Habilitation, Supported Community Residences, Accessible, Affordable, and Accountable Transportation, Employment and Volunteerism, Transition from Birth through Entire Life Span, Assistive Technology, Respite Services, Recreation, Behavior Supports, and other Support Services. The Commission supports the concept of self-directed funding such that individuals and families control the money available for their support. With regard to the implementation of self-directed funding, there are many issues to be addressed revolving around accountability for the use of federal and state funds, liability for both providers and the state, the range of funding to make available to people, and other infrastructure issues.
- The Public Relations workgroup, working with the Finance Subcommittee of the Commission, supported and participated in a public rally in January 2002, and an appreciation rally in February 2002 for the purpose of advising the Governor and the General Assembly on issues concerning the needs of individuals with mental retardation and other developmental disabilities.
- All of the existing capacity for the current fiscal year has been allocated. As of August 20, 2002, there were 1,774 individuals being supported with funding made available through initiatives of the Governor and General Assembly.

(b) Develop a statewide strategy to increase access to community-based services and supports for persons with mental retardation and other developmental disabilities. The strategy shall include:

1. Identification of funding needs and related fiscal impact; and

- Expansion funding made available in the FY 01-02 biennium was allocated to serve 500 additional people in the Supports for Community Living waiver. Of that number, 217 had lost their caregiver(s) and were determined to meet the emergency criteria; the remainder, 283, had been on the waiting list, some for as long as sixteen years (since September 1984).
- The Commission determined that \$33,371,000 in State General funds would be needed for the FY 03-04 biennium, as a next step in building a capacity to serve 8,000 people within the 10-year time frame. Priority was given to funding an additional 500 people in the SCL program.

- In keeping with the priority set by the Commission, expansion funding for the SCL program has been included in the Governor's spending Plan for FY 03. Both the House and Senate support continued expansion for FY 04. New State General Funds allocated for FY 03 were in the amounts of \$1.97 million (\$6.5 million with the federal match) for the Supports for Community Living waiver, and \$0.2 million for the Supported Employment program. These new SCL funds will serve 500 additional people over the current biennium, which includes the first two years of the 10-year plan. This new funding meets the 10-year commitment to serve 500 new people in SCL; and represents the highest priority of the Commission. New funding to serve individuals through a low cost waiver (200 people), and a state funded program (1000), has not been made available.

2. Criteria that establishes priority for services for individuals approved for slots that consider timeliness and service needs;

- The Commission created a special subcommittee to focus on this issue. During the period of months the subcommittee met, several changes were made in the Medicaid regulation regarding emergency criteria, based on the subcommittee's recommendations. The revised emergency criteria are as follows:
 - Death of the historic primary care provider that threatens the health, safety, and welfare of the individual;
 - Verifiable loss of the historic primary care provider due to incapacitation or abandonment that threatens the health, safety, and welfare of the individual; or
 - Attainment of the age of twenty (20) years and six (6) months, and in the custody of the Department for Community Based Services.
- The subcommittee approved these changes. In its final report to the Commission, the subcommittee recommended "that a structured, weighted system be developed that would establish an individual's placement on the registry (waiting list)". However the subcommittee felt that "until such time as more adequate resources become available, it is not prudent to develop, implement, and update an administratively complex and costly system to determine the needs of individuals. Currently, the emergency criteria are very restrictive, yet there continues to be a waiting list for individuals in emergency situations. In order for individuals to have adequate access, it is crucial that there be additional funding for the Medicaid waiver as well as for state funded programs. . ."
- Although funds for the administrative expansion of this activity remain limited, these recommendations have remained a priority of the

Cabinet for Health Services, and workgroups have continued to refine access to and management of the waiting list. Implementation of the revised structure is planned for 2003.

- On an annual basis, the waiting list is updated to assure accurate information exists for those who are waiting for SCL services. As of August 15, 2002 there were 2,168 people who had applied for services. Although these individuals have applied for SCL services, other supports are being made available through other programs. A review of other funding sources for the people on the waiting list yielded the following information.

A cross check with the Medicaid database indicates that, in FY 02, approximately 79% of the individuals were currently receiving some level of Medicaid at an estimated cost of approximately \$30 million.

- 129 were in ICF/MR facilities at an estimated average cost of \$95,000.
- Another 36 were in private nursing facilities at an estimated average cost of \$55,600.

Additionally, there are State General Funds that support services for individuals on the waiting list. In FY 02:

- They received more than \$4 million in services provided by or through Community Mental Health/Mental Retardation Boards.
- Individuals on the waiting list received approximately \$900,000 in services through the Supported Living program.

- Based on the information obtained as a result of the most recent waiting list update other information revealed:
 - Prior to the expansion funding becoming available, 30% of caregivers of individuals waiting for services were over the age of 60. Because of the initiatives cited above, funding has gone to support those most in need and currently this percentage has been reduced to 24%.
 - 64% are currently living with family or a relative, 15% live in a group home or personal care home, while 7% live in their own home or apartment.
 - For 73% of the people, the mother is the primary care giver; and 6% indicate the father.
 - 61% of the people indicate they have a case manager and 84% rate them as either good or great.

KRS 210:577: (c) Assess the need and potential utilization of specialized outpatient clinics for medical, dental, and special therapeutic services for persons with mental retardation and other developmental disabilities;

- The Commission created a special subcommittee to focus on this issue. The subcommittee determined that:
 - There is a lack of qualified or experienced medical, dental and therapeutic professionals;
 - Individuals and their families have difficulty accessing these services; and
 - There is a lack of interest in, and lack of education and awareness about serving individuals with mental retardation and other developmental disabilities.

Therefore, the funding for an outpatient clinic was included in the funding request put forth by the Commission.

- Funds within the Department for Mental Health and Mental Retardation Services are being redirected to support an outpatient dental clinic and center of excellence in dental education. The services of this clinic will be made available to individuals with mental retardation and other developmental disabilities who, because of their disability, have had limited access to dental services. The clinic will include a strong educational component. In affiliation with the University of Louisville, it will be a teaching/training center for dental residents and for dentists interested in continuing education. The target date for the delivery of clinical services is October 1, 2002.
- Additionally, the Department of Mental Health and Mental Retardation Services submitted a grant request to the Robert Wood Johnson (RWJ) Foundation's State Action for Oral Health Access Program to assist with funding this initiative. The RWJ grant was designed to expand the Fellowship opportunities between the Clinic and the University of Louisville, and to support the publication of a practice manual for specialized dentistry. On August 16, 2002, notification was received that the grant was not funded.

KRS 210:577: (d) Evaluate the effectiveness of state agencies and public and private service providers, including nonprofit and for-profit service providers in:

1. Dissemination of information and education;

- The Commission meetings are public meetings, and have had the regular attendance of 60-80 guests. Many of those in attendance represent regional and statewide advocacy groups and providers.
- The Department of Mental Health and Mental Retardation Services has a dedicated website for the Supports for Community Living waiver, and

other services supported by the Division of Mental Retardation, such as Supported Living. In addition, two other websites have been developed by the Cabinet for Health Services, one to provide information on the progress and status of the Olmstead planning initiative; the other, KyCARES, is an online services/information directory and guide of federal, state and local community providers of basic services.

- The outreach efforts conducted by the state have been mirrored by public and private providers for the people within their communities.
- The Commission's recommendations include funding for a Central Point of Contact who would act as a focal point for resources and information for a specific region. As additional funds have not been provided for this function, the Division of Mental Retardation has redirected the efforts of existing regional liaison staff to function as a regional contact. In addition, Area Administrators act in this capacity for people in the Supports for Community Living waiver.

2. Providing outcome oriented services; and

- The Division of Mental Retardation conducts annual interviews with people who are receiving supports for the purposes of determining the outcomes of those services. The Commission's recommendations include the funding of additional consumers and families in quality assurance activities.
- In a 2001 survey of individuals receiving services:
 - 85% indicated they were happy with their lives
 - 90.9% indicated they liked their work or day program
 - 91.5 liked where they lived, and
 - 78.3% said they had friends who were not staff or family.

3. Efficiently utilizing available slots and resources, including blended funding streams;

- Over the last biennium, 500 new placement allocations were funded and distributed to individuals. Of these, 454 people are receiving their chosen supports and services, and 46 people are still in the process of developing supports.
- For FY 03, letters were sent during the first quarter of the fiscal year to 250 individuals who were on the waiting list; 135 of those individuals live in the community, and 115 want to move from a facility to the community. The increase in the number of people wanting to move

from an ICF/MR (facility) to the community is, in part, a response to the state's effort to the Supreme Court's Olmstead decision. This decision emphasizes that people in facilities have the option and opportunity to choose their living environment, including the community. Within the past 18 months, a variety of educational efforts have been undertaken to assure that individuals and their guardians are able to make an informed choice. These efforts resulted in a number of people being added to the waiting list. In accordance with the regulations, the date assigned to their application to the SCL program was September 22 1995, if they were admitted to a facility on or before that date. Since the majority of these individuals were admitted to the ICF/MR many years ago, they were given a 1995 date. The names of individuals residing in facilities have been placed on the regional waiting lists of their regions-of-origin (as opposed to the regional waiting list of the region in which the facility is located).

- Because of a historical lack of funding, service providers have been limited. Through training and information efforts, additional providers have been recruited. Since March 2001 through June 2002, the number of Supports for Community Living providers has increased from 63 to 106. Forty-three additional provider applications are in process. The presence of additional providers has given people more choice in what supports they receive and choice in who serves them.

KRS 210:577: (e) Develop a recommended comprehensive ten (10) year plan for placement of qualified persons in the most integrated setting appropriate to their needs;

- Kentucky's Plan: From Dreams to Realities for Quality and Choice for All Individuals with Mental Retardation and Other Developmental Disabilities was submitted to Governor Paul E. Patton and the General Assembly on April 17, 2001. Highlights of the plan include efforts related to: Prevention, Promoting Choice, Promoting Quality, Promoting Access, and Financing the System. The planning process involved hundreds of people representing a broad range of stakeholders. Elements of the Plan have been incorporated into the strategic planning process of the Department and Cabinet. The Plan has broad support, is a dynamic and moving document, and continues to be the blueprint for the Commission's work.

KRS 210:577: (f) Recommend an effective quality assurance and consumer satisfaction monitoring program that includes recommendations as to the appropriate role of family members, persons with mental retardation and other developmental disabilities, and advocates in quality assurance efforts;

- The Commission recommended that family members, persons with mental retardation, and advocates be included in quality initiatives and monitoring activities at the state and local/regional levels. It was recommended that the current Core Indicators Project be expanded. This project utilizes a national instrument in assessing client satisfaction, safety and quality of life. Rather than relying on a professional surveyor, the Commission recommended a survey team, which includes a professional and a consumer or family member.
- The Cabinet for Health Services applied for and received a \$2 million federal grant from the Centers for Medicare and Medicaid Services (CMS) to aid Kentucky in making long-lasting changes in the delivery of community supports to persons with disabilities and long term health care needs. The grant focuses on improving housing, quality services and workforce development. A component of the grant is to work with persons with disabilities and their families to develop and implement effective quality outcomes from the consumer standpoint. The Cabinet is partnering with three core advocacy groups to help develop a consumer voice in evaluating the quality of services based on the belief that the consumers and family members know best what services they need and whether or not the services are meeting their needs. These efforts reach out to consumers and family members to assist the state in determining what consumers and family members consider quality services.

These efforts include:

- A consumer led model for monitoring will be developed, which will be guided by the principles of self-determination, person-centered planning, and informed decision making/choice.
 - Self-advocates and family members will be recruited and trained to be members of two-person interview teams for consumer satisfaction.
 - Volunteer personal advocates for 50 individuals served by the Supports for Community Living waiver program will be recruited to help assure individual choice, participation, competence enhancement and respect.
- In addition to family and consumer involvement in community programs, some of the ICFs/MR have enacted ongoing monitoring reviews by family members and volunteers who visit the facility. These actions have enabled timely identification of issues, and have been a valuable component for facility improvement. Portions of the reports are shared with Governing Board(s).

KRS 210:577: (g) Advise the Governor and the General Assembly on whether the recommendations should be implemented by administrative regulations or proposed legislation for the 2002 General Assembly.

- The most significant piece of legislation affecting the work of the Commission was House Bill 1, the budget bill. This bill included substantial additional funding for the SCL Waiver program. In spite of revenue shortfalls, the support of individuals with mental retardation and developmental disabilities was one of the Governor's "promises kept". This element of the budget continues to receive widespread bipartisan support.
- Pending more work by the Commission, additional regulatory amendments will be requested regarding criteria to be used in prioritizing the waiting list.
- Senate Bill 185, which was passed in the 2002 General Assembly, allows ICFs/MR to establish beds that are reserved for respite, without obtaining a Certificate of Need. These beds will provide a much needed service.

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